Human functioning in health care

Stallinga, Hillegonda Alida

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General discussion

8.1 Introduction

The results of the studies presented in this thesis contribute toward the implementation of the concept of functioning in health care. The results are relevant to current health care provision, which faces an aging population that has one or more non-communicable chronic diseases. In this respect, a person's functioning seems the most promising target for supporting his/her well-being.[1] The concept of functioning also fits the proposed definition of health, which states that "health is the ability to adapt and self-manage in the face of social, physical, and emotional challenges".[2]

The World Health Organization (WHO) uses the term functioning as a basic concept in the International Classification of Functioning, Disability and Health (ICF).[3] The ICF was published in 2001 by the WHO as the international standard terminology for functioning and environmental factors. It was published together with the conceptual model of health (Figure 8.1), which is based on the biopsychosocial model.[4]

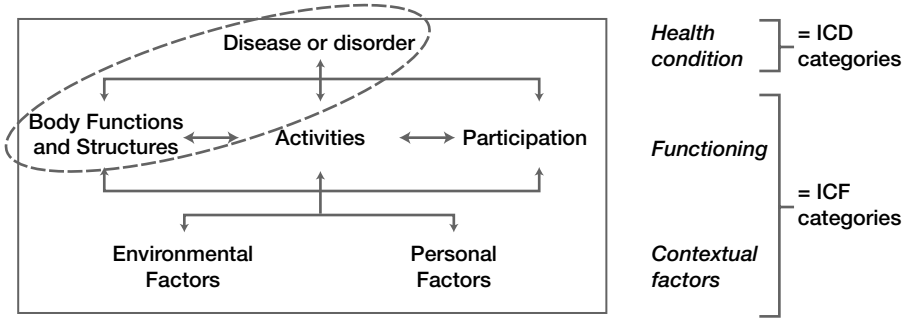

Figure 8.1 WHO's conceptual model of health representing the interactions between the components[a] of the health status.[4] Note the partial perspective of health based on the biomedical model (oval) vs the holistic perspective of health based on the biopsychosocial model (rectangle).[5] ICD: International Classification of Diseases; ICF: International Classification of Functioning, Disability and Health.

Current health care is based on the biomedical model, which focuses on diseases or disorders in body functions and structures (Figure 8.1).

[a]Components refer to all elements of the conceptual model including body functions and structures, activities and participation as well as environmental factors, personal factors, and health condition.

Implementation of functioning in health care means that the current *biomedical* focus on health care has to be broadened to a biopsychosocial focus. In a *biopsychosocial* model, which is based on the holistic perspective,[6,7] all components of the conceptual model of health are taken into account to reach a person's best state of health.

The aim of this thesis was to explore the inclusion of the concept of functioning as an important focus in health care by means of applying the standard terminology of the ICF and the conceptual model of health. The standard terminology aims to improve communication, and the conceptual model aims to facilitate clinical decision-making.[4] By studying these two topics as two inseparable but distinct aspects of functioning, specific information can be obtained, relevant for developing effective strategies for the implementation of the concept of functioning in health care.
To achieve this aim, three research questions were formulated:

1. To what extent does language ambiguity regarding functioning exist in clinical practice and research and what are the consequences for communication?
2. To what extent does the use of standard terminology for functioning and the conceptual model of health facilitate clinical decision-making and what are the effects on clinical practice?
3. To what extent are health care professionals focused on functioning in health care and what is their opinion on the usefulness of this concept in their clinical practice?

8.2 Main findings

To answer the first research question, two studies were conducted. The first study is a literature review that analyzed the use of ambiguous language regarding functioning in clinical practice (Chapter 2). The second study is a cross-sectional survey that analyzed the effects of different assessment tools regarding participation as an aspect of functioning in 677 patients with a neuromuscular disease (Chapter 3).

The literature review used the standard terminology of the ICF to identify aspects of functioning related to language use in clinical practice. The results demonstrated that language ambiguity regarding patients' functioning

existed. However, problems related to language ambiguity were not found. The absence of problems experienced by health care professionals may explain the lack of success of many projects aimed at implementing standard terminology concerning functioning in clinical practice.[8]

The cross-sectional survey used the standard terminology of the ICF to identify the operationalizations of the concept of participation in six different assessment instruments. The conceptual model of health was used in a regression analysis in which participation was the dependent variable and the predictors were the components of disease, body functions, activities, and contextual factors. We found that participation was predicted by different components of the conceptual model depending on the operationalization of participation. To be able to compare research outcomes, consensus on the definition of the concept of participation is needed. It was concluded that participation is an ambiguous concept in research, and this ambiguity makes evidence-based decisions directed at enhancing participation difficult.

The results of these two studies demonstrated that functioning is still an ambiguous concept in clinical practice and in research. Although we did not find negative consequences of language ambiguity for clinical practice, research was hindered by language ambiguity.

To answer the second research question, two studies were conducted: a qualitative study in which the content validity of the ICF core set[b] for neuromuscular diseases (NMD) was examined (Chapter 4); and a study in which data from a randomized clinical trial in 81 patients with multiple sclerosis (Chapter 5) were analyzed regarding clinical decision-making.

The qualitative study linked concepts of existing disease-specific Health-Related Quality of Life (HRQOL) questionnaires to the ICF standard terminology and compared these with the initial ICF core set for patients with chronic neurological disorders. We found that the concepts in the existing HRQOL questionnaires were covered by the initial ICF core set. In fact, the NMD core set covered an even broader scope of health-related concepts in patients with neuromuscular disease compared with the concepts in the HRQOL questionnaires. These concepts were relevant to clinical decision-

[b]An ICF core set is a selected set of ICF categories, related to a specific health condition. This set can serve as a minimal standard for the assessment and reporting of functioning and health for that specific health condition.[57]

making, especially regarding participation and environmental factors.

The study described in chapter 5 investigated the effects of using the ICF core set for clinical decision-making in practice. The Multiple Sclerosis Impact Profile (MSIP),[9,10] a validated ICF core set for patients with multiple sclerosis, was used in a randomized controlled trial testing the effects of the use of a functioning assessment in combination with a biomedical assessment in 81 patients with multiple sclerosis.[11] Compared with the biomedical assessment, the combined assessment resulted in the registration of a significantly higher number of problems experienced by patients in the components participation and environmental factors and a significantly higher number of professional health care activities related to these components. Use of the functioning assessment in combination with the biomedical assessment resulted in a positive correlation between registered problems by health care professionals and patients' self-reported problems, In contrast, use of the biomedical assessment alone resulted in several negative correlations.

Based on these two studies, it can be concluded that the standard terminology of the ICF and the conceptual model of health facilitate clinical decision-making in practice and have positive effects on the promotion of patients' health, especially regarding the components participation and environmental factors.

To answer the third research question, two studies were conducted. First, an exploratory mixed-method study was performed that analyzed 413 graduate theses of Master of Advanced Nursing Practice (MANP) students. The second study concerned a randomized controlled trial that analyzed the effects of a training in using the ICF in 74 students of the MANP. The participants of both studies were nurse practitioners because they are assumed to integrate cure (disease) and care (functioning) in clinical practice.[12,13]

The mixed-method study examined the professional focus of graduates of the MANP by analyzing graduate theses in terms of cure and care (Chapter 6). The topics of the graduate theses were classified in the components of the conceptual model of health. About half of the graduate theses could be classified in the conceptual model. Of the theses that were classified in the conceptual model, approximately half were focused on cure, one-third on the intersection of cure and care, and the remaining number on care. This indicates that only a minority of the nurse practitioners were focused on the

intersection of cure and care in their MANP graduate theses. Therefore, to support the assumed integration of cure and care in clinical practice by nurse practitioners, the conceptual model of health and the standard terminology for functioning should be included in their education program.

The final study (Chapter 7) explored the opinion of students enrolled in the MANP regarding the usefulness of the ICF in clinical practice. The effects of a short ICF training were studied in a randomized controlled trial. The primary outcome measure was attitude toward the ICF, for a positive attitude is a prerequisite for effective learning.[14] The perceived usefulness of the ICF was a subscale of attitude. The ICF training resulted in a significantly larger increase in perceived usefulness of the ICF immediately after the ICF training compared with the control group. At 3 months follow-up, however, there was no longer a statistically significant difference between both groups. These findings indicate that while a short ICF training increases usefulness, a more comprehensive ICF training is required to establish long-term effects.

Based on these two studies, it can be concluded that a limited number of MANP graduates were focused on functioning, which was reflected by their choice of thesis topic. Training in using the ICF, including the conceptual model of health, increases the perceived usefulness of the ICF in MANP students.

8.3 Reflections on this thesis

Functioning has been recognized and operationalized by the ICF, and numerous research projects on the application of the ICF have been conducted.[15,16] However, the inclusion of functioning as a focus in health care had yet to be explored.

Implementing functioning in health care is multidimensional. Many aspects are involved, including organization of health care, education of professionals, guidelines, tools, effects on patients, and financial issues.[17] This thesis only addresses six aspects. It builds on previous studies in which the application of the ICF was aimed at linking measurement instruments to the ICF[18,19] and at developing ICF core sets.[20] In the last decades more than 30 ICF core sets have been developed[21,22] and several instruments are linked to the ICF.[23-29] The overall conclusion of previous studies is that the ICF provides a comprehensive and complete standard terminology in a convenient structure

for the description of functioning.[15,16] This conclusion formed the basis for our research, which aimed to extend the application of the ICF to the focus on the concept of functioning in health care. The exploration of the use of the standard terminology of the ICF and the use of the conceptual model of health as two distinct but inseparable topics makes this thesis unique. The implementation of the ICF in clinical practice has not been successful always.[30,31] This lack of success was confirmed in our study (Chapter 2). The results of this thesis demonstrated that making a clear distinction between the use of the standard terminology of the ICF and the use of the conceptual model is a promising approach to the implementation of the concept of functioning in health care.

A limitation of this thesis concerns the generalizability of the results. The results related to assessment tools are valid for patients with neuromuscular diseases (Chapter 4) and patients with multiple sclerosis (Chapter 5). The results related to the focus on and the opinions on functioning are valid for nurse practitioners (Chapter 6 and 7). With regard to the results on language ambiguity (Chapter 3), comparable outcomes were found in a study in patients with chronic liver failure.[32]

8.4 Synthesis of findings

This thesis addresses the distinction between use of the standard terminology and use of the conceptual model of health when focusing on functioning in health care.

Emphasizing the use of the conceptual model could be the solution for the lack of success of the implementation of ICF in clinical practice.[30] In this respect, we endorse the observation of Dahl[33] that the title of the ICF might be misleading. What exactly is meant by the use of the ICF in clinical practice? The standard terminology or the conceptual model? Furthermore, the conceptual model is not merely confined to the ICF because health conditions (the ICD) are also included. Preferably, the conceptual model of health and the standard terminology of the ICF should be separated by the WHO. Such a separation also warrants a consideration of the specific qualities of both the standard terminology of functioning and the conceptual model of health as well as their relationship.

The value of standard terminology[c] has been acknowledged for the fields of research and data aggregation[34] (Chapter 3 and 4). A well-known nursing adage states that "If we cannot name it, we cannot control it, practice it, teach it, finance it, or put it into public policy".[35] The standard terminology of functioning of the ICF provides the basis for naming, controlling, teaching and so forth.[4] For clinical practice, however, the use of unambiguous language is not a valid argument to introduce standard terminology, even when language ambiguity is present (Chapter 2).

A specific feature of the conceptual model of health concerns its fit with the biopsychosocial model. The biopsychosocial aspects are represented in the components of the conceptual model (Figure 8.1). The figure displays that the current *biomedical* model will be broadened to include the *biopsychosocial* model with the components activities and participation and contextual factors. The conceptual model is useful in clinical practice and supports the focus on functioning in health care provision (Chapter 5 and 7). To date, the biopsychosocial model is not incorporated in clinical practice despite its acknowledged relevance for health care.[7,17,36,37] A possible explanation could be the insufficient concreteness of the components of the biopsychosocial model. This holds especially true for those components related to the *psychosocial* extension of the *biomedical* model. The conceptual model of health and the terminology of the ICF can make these components more concrete. Social aspects, for example, are operationalized in the component of participation with ICF categories related to interpersonal interactions, major life areas, and community life. Both the standard terminology and the conceptual model of health are required for the implementation of functioning, i.e. the biopsychosocial model, in health care.

Clinical decisions should be the result of clinical reasoning,[38,39] which includes assessment, goal setting, interventions, and evaluation. The conceptual model of health and the standard terminology of functioning help professionals to focus on patients' biopsychosocial aspects in all these phases (chapters 5 and 7).

Finally, the mindset of health care professionals is not yet focused on functioning in health care (Chapters 4 and 6). In addition, a focus on

[c]A standard terminology is a selected set of terms, each with a discrete meaning, arranged in a specific structure aimed to provide unambiguous use of language with regard to a specific phenomenon.

functioning does not easily fit in with the current predominant biomedical health care system.[17,40] Health care professionals, including nurses, therapists, and physicians, deliver their care to patients by using tools and skills predominantly embedded within the biomedical model.[41] Tools (Chapters 4 and 5) and training (Chapter 7) related to functioning are therefore a prerequisite for health care professionals to be able to focus on functioning, i.e. the biopsychosocial model, in clinical practice.

8.5 Practical implications

The findings of this thesis have several implications for clinical practice, education, financing, and evaluation of health care as will be discussed below.

Clinical practice
The conceptual model of health enables health care professionals to address functioning in their clinical decision-making. In a *biopsychosocial* model, the goal setting of the patients themselves is the guiding principle, whereas disease and the related disability are the guiding principles in the *biomedical* model. The ICF enables health care providers to assess patients' goals in terms of functioning. This type of clinical decision-making requires the involvement of the patient and it gives patients the opportunity to consider, in cooperation with the health care professional, different solutions for health challenges.

Education
To implement the focus on functioning in health care, health care professionals have to be educated and trained. To make the implementation successful, a paradigm shift is needed from a biomedical orientation to a biopsychosocial orientation.[42] The education and training should include all health care professionals, not only physicians, nurses, and therapists, but also educators, politicians, administrators, and society at large. The implementation of the biopsychosocial model in clinical practice is challenging for health care professionals, especially for those who have not received training in biopsychosocial theory and its application.[43]

The main goal of the training is to provide participants with knowledge and skills that enable them to use the conceptual model and the standard

terminology of the ICF as practical tools in daily practice.[44] A few training programs on the use of the ICF already exist,[43,45,46] including a program that was developed in the Netherlands.[47] This four-month training course consists of three instructor-led training days together with distance learning. Training groups consist of twelve participants and two teachers. For distance learning between the three course days (starting day, second day, and the final day), participants are assigned to one of the two teachers. The training focuses on the conceptual model and basic principles and structure of the ICF and the application of the standard terminology in different settings. Clinical cases from participants own professional settings are presented in the conceptual model using the standard terminology. Using these clinical vignettes is one of the most fruitful ways to demonstrate the differences between the *biomedical* model and the *biopsychosocial* model. Two clinical vignettes are illustrated in Figure 8.2.

Two patients with similar health conditions and impaired body functions differ in the component of participation and the environmental and personal factors. In addition, these patients differ in goal setting: the 80-year-old woman (Figure 8.2a) wants to be part of a community and keeps in touch with her children and grandchildren, whereas the 58-year-old man (Figure 8.2b) wants to be as independent as possible and to continue to work in his business. The status of functioning of these patients and their goal setting will account for the differences in the clinical decisions and the health care provision.

Financing

The main objective of adopting the conceptual model of health and the use of the standard terminology of functioning is better health related outcomes. The primary expected impact of using functioning in health care is that patients' health will improve despite their health condition. The focus on functioning relates to participation and well-being and responds to personal expectations, skills and abilities.[48]

To date, funding of health care is supported by case mix systems and models which are based on diseases (ICD) and medical interventions.[49] In the Netherlands, this model is called a DBC (Dutch: *Diagnose Behandel Combinatie*). A DBC is a predefined average care package, with a fixed price based on a specific medical diagnosis.[50] As a consequence, there is

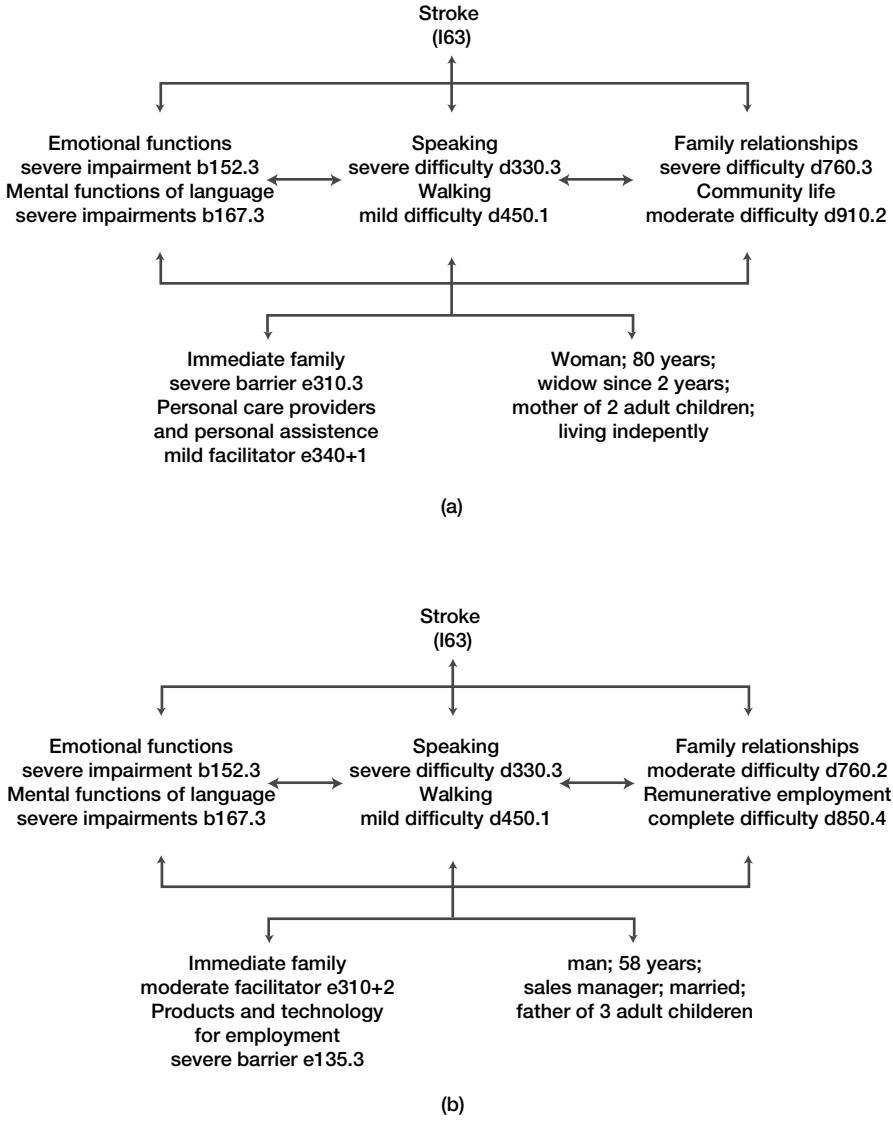

Figure 8.2 Clinical vignettes, illustrating the health status of two patients with the same health condition.

no financial incentive to achieve an improvement in functioning. To include functioning as an important focus in health care, the use of ICF categories for funding has to be explored.[49]

Evaluation of health care

While clinical practice is experiencing a shift from communicable diseases to non-communicable chronic diseases, and the health opinion is broadening its scope by focusing on 'ability', clinical practice is still using tools and skills based on the *biomedical* model.[41] A limitation is that the usefulness of the biopsychosocial model cannot be fully assessed until it is completely adopted and applied in clinical practice and research.[51] In order to evaluate the outcomes of this model, appropriate tools and interventions have to be developed. Decisions have to be made as to which intervention is needed to achieve a certain health status. When health care is evaluated in terms of disease, the best outcome is cure of the disease. The physician determines whether the outcome is reached. When health care is evaluated in terms of functioning, however, the best outcome depends on the patient and the goals he/she wants to achieve and has to be determined in cooperation with the patient.

8.6 Future research

This thesis contributes to the implementation of functioning as a focus in health care. Our findings have the following implications for future research:

- To improve the generalizability of our results, outcomes of a functioning assessment should be investigated and validated for other patient populations and other countries. This thesis provides evidence that functioning assessments based on ICF core sets in patients with multiple sclerosis lead to different clinical decisions compared with biomedical assessments (Chapter 5). The components of participation and environmental factors in particular were addressed. For generalization purposes, a number of the developed ICF core sets[3] should be tested for their effects on clinical decision-making in clinical practice. Future studies can use the electronic documentation forms available on the website of the ICF Research Branch (a partner of the WHO Collaborating Center for the Family of International Classifications (WHO-FIC) in Germany (at DIMDI).[52] The electronic forms facilitate the description of functioning based on ICF core sets for clinical practice. The forms are available in five languages, making international data collection possible.

- The existing core sets, including musculoskeletal core sets, cardiopulmonary core sets, and neurological core sets, are relevant to determining the influence of a given health condition on functioning. However, there are more aspects that influence functioning. The existing core sets have emerged from the *biomedical* perspective on health. New core sets should be developed that are related to other constructs relevant to functioning, for instance, dependency, employability, education level, mobility, or poverty.[53] Research on those constructs may provide a broader insight into interventions for improving a person's health from a *biopsychosocial* perspective.
- As described in the first chapter of this thesis, the salutogenetic perspective[54] on health focuses on how to stay healthy. More research is needed to identify the main factors of influence on health in relation to ability and disability. Persons who function successfully in daily life may provide additional insights. The LifeLines research performed at the University Medical Center Groningen (UMCG), for instance, offers the opportunity to research successful functioning in a heterogeneous population. Future studies should focus on environmental and personal factors in relation to successful functioning.
- The most important outcome related to the focus on functioning in health care is the effect of this focus on patients. To adequately and efficiently collect clinical data, mobile devices should be used.[55] The development of a mobile ICF application is currently in progress, and this application is expected to be implemented worldwide.[56] A mobile ICF application is very useful for collecting data related to functioning and contextual factors. Active involvement in and support of this kind of research is essential to make outcome evaluations of health improvement interventions possible.
- Education programs for health care professionals that focus on functioning have to be developed. Subsequently, their effects have to be determined. Further research is required to validate the ICF survey and learning assessment tool[45] used in this thesis. A validated measurement instrument for assessing learning outcomes is relevant to the development and evaluation of training and education programs.
- In this thesis the focus of nurse practitioners on the integration of cure and care was examined. For generalization purposes, however, the focus of other health care professionals should also be investigated. This

information is needed to make education and training programs related to functioning as comprehensive as possible.

8.7 Conclusions

This thesis explored the inclusion of functioning as a focus in health care by means of applying the ICF. It was found that use of the standard terminology of the ICF and the related conceptual model of health as two distinct but inseparable tools contributes to the implementation of the concept of functioning in health care.

Language ambiguity regarding functioning exists both in clinical practice and research. Negative consequences of language ambiguity were not found for clinical practice. However, language ambiguity has considerable consequences for research. The standard terminology of the ICF and the conceptual model of health facilitate clinical decision-making in practice and have positive effects on the promotion of patients' health, especially regarding patients' participation and environmental factors. Currently, MANP graduates are only focused on functioning to a limited extent, but a short training in using the ICF that includes the conceptual model of health increases perceived usefulness of the ICF in MANP students.

These findings have several implications for clinical practice, education, policy, and research. They offer potential ways to guide health care provision away from a narrow disease-based focus toward a broader focus that includes functioning as an aspect of health.

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“Niemand krijgt betaald om de patiënt gezond te hóuden.”

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